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### Supported self-management for COPD

**Citation for published version:**

Pinnock, H, Steed, L & Jordan, R 2016, 'Supported self-management for COPD: making progress, but there are still challenges', *European Respiratory Journal*, vol. 48, no. 1, pp. 6-9.  
<https://doi.org/10.1183/13993003.00576-2016>

**Digital Object Identifier (DOI):**

[10.1183/13993003.00576-2016](https://doi.org/10.1183/13993003.00576-2016)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

European Respiratory Journal

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**Supported self-management for chronic obstructive pulmonary disease: making progress, but there are still challenges**

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|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Journal:                      | <i>European Respiratory Journal</i>                                                                                                                                                                                                                                                                                  |
| Manuscript ID                 | ERJ-00576-2016                                                                                                                                                                                                                                                                                                       |
| Manuscript Type:              | Editorial                                                                                                                                                                                                                                                                                                            |
| Date Submitted by the Author: | 20-Mar-2016                                                                                                                                                                                                                                                                                                          |
| Complete List of Authors:     | Pinnock, Hilary; University of Edinburgh, Allergy and Respiratory Research Group, Centre for Population Health Sciences<br>Steed, Liz; Queen Mary University of London, Centre for Public Health and Primary Care<br>Jordan, Rachel; University of Birmingham, Unit of Public Health, Epidemiology and Biostatistics |
| Key Words:                    | chronic obstructive pulmonary disease, Supported self-management, Multimorbidity, exacerbations of COPD, behaviour change                                                                                                                                                                                            |
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**Supported self-management for chronic obstructive pulmonary disease: making progress, but there are still challenges**

Hilary Pinnock [hilary.pinnock@ed.ac.uk](mailto:hilary.pinnock@ed.ac.uk)  
Allergy and Respiratory Research Group, Usher Institute for Population Health Sciences and Informatics, The University of Edinburgh, UK

Liz Steed [e.a.steed@qmul.ac.uk](mailto:e.a.steed@qmul.ac.uk)  
Centre for Public Health and Primary Care, Queen Mary University of London, UK

Rachel Jordan [r.e.jordan@bham.ac.uk](mailto:r.e.jordan@bham.ac.uk)  
Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, UK

Address for correspondence  
Dr Hilary Pinnock  
Reader,  
Usher Institute for Population Health Sciences and Informatics,  
The University of Edinburgh  
Doorway 3, Medical School, Teviot Place,  
Edinburgh EH8 9AG  
Tel: 0131 650 9474  
Fax: 0131 650 9119  
E-mail: [hilary.pinnock@ed.ac.uk](mailto:hilary.pinnock@ed.ac.uk)

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3 Respiratory specialists, familiar with the success of supported self-management in  
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5 asthma,[1] may be excused for feeling disappointed by the evolution of evidence in  
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7 chronic obstructive pulmonary disease. The promise of early studies [2-4] was  
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9 seemingly dashed by a series of negative trials [5,6] and even a trial terminated early  
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11 for fear of a detrimental effect.[7]. The most recent Cochrane review, however,  
12  
13 concludes that interventions to support self-management reduce respiratory-related  
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15 and all-cause admissions, reduce dyspnoea and improve quality of life.[8] The  
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17 interventions in the included studies were heterogeneous and complex; and it was  
18  
19 not possible to identify the individual components of supported self-management  
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21 responsible for effective outcomes. A wider review of trial-level data was also  
22  
23 unable to identify the most important components.[9] The report by Jonkman *et al*  
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25 in this issue of the journal, which explores the characteristics of effective self-  
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27 management interventions in an individual patient data meta-analysis, is therefore a  
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29 useful contribution to the literature.[10]  
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### 39 *Difficulty identifying early exacerbations*

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42 In retrospect, the clues that self-management in COPD would be more challenging  
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44 than in asthma were already available. From the health service perspective, one of  
45  
46 the main goals of self-management is to enable patients to recognise that their  
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48 condition is deteriorating and take timely, appropriate action that can prevent  
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50 further development of an exacerbation and reduce the risk of an admission.  
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53 However, qualitative studies in people with COPD highlight the difficulty people have  
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55 in distinguishing 'bad days' from the onset of an exacerbation observing that it is  
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‘only afterwards that you know you are not well’.[11] When asked about the symptoms that indicate an exacerbation, many patients describe nebulous symptoms of ‘just feeling rough’;[12] an observation that will resonate with any general practitioner who has been asked to visit a COPD patient in the throes of an exacerbation whose complaint is no more specific than ‘unwell’. Analysis of telemonitoring data suggests that it is the minority of patients who can log discrete episodes of increased breathlessness, cough and purulent sputum.[13] Most experience a rolling pattern of on-going symptoms with little clarity on when treatment is appropriate. This difficulty in distinguishing the onset of an exacerbation may be one reason for the negative findings of Bucknell *et al*’s trial of self-management.[6] They observed that only 42% of participants were ‘successful self-managers’ – and (in a post-hoc analysis) showed that the intervention was effective in this sub-group. Calverley *et al* predicted this difficulty from analysis of diary cards from trial participants.[14] Despite an increase in mean symptom scores, on an individual patient basis, concurrence between an exacerbation event and a change in breathless, chest tightness, cough and night waking was evident in less than half of the patients. Successful self-management in COPD must go beyond symptom recognition and treatment response.

*Living with COPD*

People with any long-term condition, even if they attend regular reviews with their healthcare professionals, are responsible for their own care for the majority of the time – they are *de facto* ‘self-managing’. For the patient this is more than a narrow

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3 biomedical approach to detecting and managing exacerbations. A commonly cited  
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5 definition of self-management includes having the confidence to deal not only with  
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7 medical management (the focus of the cited systematic reviews [8-10]), but also the  
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9 role and emotional management of their condition(s).[15] For people living with a  
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11 chronic disabling condition such as severe COPD, coping with day-to-day activities -  
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13 walking, dressing, eating - may be the priority self-management skills. Support for  
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15 changing health behaviours (sustained smoking cessation and increased activity) is  
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17 crucial. This resonates with successful self-management interventions in other  
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19 chronically disabling conditions (e.g. stroke), that focus on strategies for enabling  
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21 and improving behaviours and activities of daily living rather than crisis  
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23 management.[16,17] Qualitative work has highlighted how people with severe  
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25 COPD struggle with (and adapt to) the change in roles imposed by their  
26  
27 condition.[18] Despite being aware of their difficulties, they fear being seen as  
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29 'needy' and will eschew professional care in favour of (reluctantly) seeking the help  
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31 of family/friends to enable them to continue living independently.[19] Self-care in  
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33 this broader sense is a key motivator for many people with long-term conditions and  
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35 may be harnessed to encourage engagement in the more clinical model of self-  
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37 management described in systematic reviews.  
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49 Underlying these broader aspects of self-management are the individual's illness and  
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51 treatment beliefs, which have consistently been shown to be important predictors of  
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53 quality of life and disability.[20] Identifying and responding to beliefs (such as low  
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sense of control, inappropriate attribution of symptoms, and high emotional perceptions) should therefore be central to self-management support.

*On-going support for self-management*

Taxonomies of self-management support derived from studies in a range of long-term conditions have identified components reflected in the COPD self-management literature.[17] Jonkman *et al* sought to identify components of the interventions associated with a positive outcome and concluded that only the duration of the intervention showed consistent associations with all-cause admissions. The longer the intervention was supported by professional review (range 1 day to 24 months) the greater the reduction in admissions. This resonates with the findings of the meta-analysis from Jordan *et al* which suggested that interventions that were more supported by health-care professionals improved quality of life and reduced admissions.[9] Proponents of self-management will interpret this as a dose response to the self-management intervention; cynics may speculate that the active ingredient was the professional review rather than the self-management. The truth probably lies in a combination of these explanations. Self-management is not a single event; for behaviour change to be maintained continued support is crucial. We observed the gradual evolution of self-management skills in the qualitative evaluation of ‘Light Touch’ COPD monitoring in which the daily oversight of telemonitoring was replaced by a helpline; over six months patients gradually gained confidence in managing their own condition.[21]

### *The challenge of multimorbidity*

The final challenge for COPD self-management is that the majority of patients have co-morbidity and half will have multiple morbidities,[22] some of which may be a higher priority for them than their COPD. Common co-morbidities are coronary heart disease, depression and anxiety, and pain;[22] any of which may limit day-to-day activities and mask symptoms of deterioration. There is no clear guidance on self-management advice appropriate to patients with multi-morbidity. Demands from different conditions may conflict or confuse and individually tailored professional advice may be needed to help people with multimorbidity live optimally with their conditions and, more specifically, interpret and respond to deteriorating status.

### *A whole systems approach to supporting self-management*

Jonkman *et al*'s conclusion reminds us that supported self-management is not a time-limited intervention delivered as a once and for all package. It is not a 'thing' to be given to a person with COPD (or any long-term condition) but an on-going process of joint understanding, reviewing and problem solving so that advice can be refined to help a person live better with their condition(s). This needs a whole systems approach for effective implementation.[1,23] Responding to patients' beliefs and priorities, provision of information and resources are essential (in our work a key request from people with COPD was for information about community resources and self-help agencies [24]) with support tailored to the individual's clinical, demographic and psychosocial characteristics. Practitioners need not only to be knowledgeable about COPD but also skilled in patient-centred consulting. Crucially it demands that the healthcare system is configured to support self-management;



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address the multimorbidities with which the patient is living; provide flexible access to professional advice;[25] and ideally ensure continuity of care.[26]

In practical terms, this will have to be achieved within the routines of existing healthcare services and the resources available. Self-management is currently supported within holistic pulmonary rehabilitation programmes (though access and uptake are challenging [27]); strong primary care systems have the potential to facilitate on-going support, patient charities could contribute to the broader aspects of living with COPD, and in the future technological approaches to care delivery may improve efficiency.

*Conclusion*

Jonkman *et al's* individual patient data meta-analysis adds support to the increasing evidence that supported self-management can reduce admissions,[8,9] and highlights that interventions involving on-going professional support were more effective in reducing admissions.[10] There are however, significant unresolved challenges for patients, professionals and healthcare systems. Clinical 'action plans' do not reflect the difficulties patients have in identifying the onset of an exacerbation and rarely consider the impact of multimorbidity. As well as medical self-management, patients (and their carers) need advice to support the psychosocial challenges of living with the chronic disabilities of COPD, and health care professionals must be skilled to elicit and respond to the patients' perceptions and priorities.[28] Healthcare systems must adapt their services to providing on-going flexible support for self-management within financial and resource constraints.

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3 Finally, we need to measure success not only by the health service priority of  
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5 reducing admissions, but also aspects of general well-being and markers of  
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7 independent living as we seek to support people living for many years with the  
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9 disability of COPD and other long-term conditions.  
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